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Research Challenges and Lessons Learned from Conducting Community-Based Research with the Hmong Community

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Abstract

Background—Conducting research with underserved communities with little exposure to research presents a number of challenges and opportunities. Our study used a community-based approach to better understand factors that influence breast and cervical cancer screening among Hmong women.

Objective—This article shares lessons learned during the process of developing and conducting qualitative research with a Hmong community with limited experience with research.

Methods—We conducted 17 key informant and 84 in-depth interviews with Hmong women and men. Research team discussions, insights from Hmong research team members, input from our Community Advisory Committee, and project documents were sources of information about the process of conducting research in this community.

Results—Lessons learned concern including a cultural insider as an investigator; building community partnerships and support; establishing and working with a community advisory committee; hiring and training bilingual, bicultural staff; and using culturally appropriate materials and methods in a small, kinship-based community. We used multiple strategies to ensure this study was conducted in a culturally appropriate manner.

Conclusion—The lessons learned from our experiences can provide guidance to researchers on methodological and practical issues in conducting research with the Hmong and can inform future research with the Hmong and other similar underserved populations.

Introduction

Community-based research is rooted in engaging community members and academic researchers equally and recognizing the unique strengths that each brings (Israel, Schulz, Parker, & Becker, 1998). According to Israel and colleagues (1998), the term “community-based” research has been used interchangeably with terms such as “community-wide,” “community-involved,” or “community-centered” research, and more recently “community-

based participatory research” (CBPR). Community-based research is an approach that lies along the CBPR continuum such that not all guiding principles of CBPR apply, but that community-based research begins with a health issue or concern that is important to the community and is conducted with a community and not just in community settings. These approaches (e.g., community-based research, CBPR) have been shown to work toward the reduction of health disparities in vulnerable populations (Israel et al., 1998; Minkler & Wallerstein, 2002). Community-based research emphasizes conducting research with communities in which members actively participate in all aspects of the research process (Israel et al., 1998; Schulz et al., 1998); the ultimate goal is empowering communities for social change (Minkler & Wallerstein, 2002). Other important strengths of community-based research include adding credibility to the study by integrating community input, which can foster trust between academic researchers and the community (Minkler & Wallerstein, 2002).

Using community-based research, we conducted a two-year exploratory study of influences on breast and cervical cancer screening with the Hmong population in Oregon. Most Hmong immigrated to the United States starting in 1975 following the end of the Vietnam War (Hamilton-Merritt, 1993; Yau, 2005). Many came to the United States from refugee camps in Thailand to which they had fled from Laos (Hamilton-Merritt, 1993). Approximately 260,073 Hmong live in the United States (U.S. Census Bureau, 2011). Several states, including Oregon (2,920), have Hmong populations ranging in size between 1,000 and 11,000 (Pfeifer, Sullivan, Yang, & Yang, 2012). Hmong society is kinship-based and places tremendous emphasis on lineage and clan ties for security and mutual assistance (Dunnigan & Olney, 1985; Finck, 1981). The Hmong kinship system is patrilineal and made up of 23 clans; there are 17 known clans in Oregon. Clan membership can usually be distinguished by surname. Traditionally, the Hmong values family decision-making, in particular, medical decision-making has generally been considered to be a communal act rather than an individual act (Her & Culhane-Pera, 2004; Johnson, 2002). For example, patients may seek consultation from extended family members and/or clan leaders before making a medical decision. In medical crises, family members may travel long distances to consult other family members.

Background: Health Disparities in the Hmong Population

Aside from resettlement and adjustment, the Hmong who came to the United States faced many health issues, such as post-traumatic stress disorder and depression (Culhane-Pera & Xiong, 2003). Today, health issues and societal challenges continue for the Hmong in the United States. Chronic diseases, such as cancer and cardiovascular disease, pose significant burden on the Hmong (Culhane-Pera, Moua, DeFor, & Desai, 2009; Lee & Vang, 2010). Diabetes and obesity are rapidly increasing in this population (Culhane-Pera et al., 2009; Stang, Kong, Story, Eisenberg, & Neumark-Sztainer, 2007). Stang and colleagues (2007) found that Hmong adolescents were at an increased risk for obesity and unhealthy weight control behaviors and reported less physical activity compared to White adolescents.

Cancer screening behavior is one of the most researched health topics with the Hmong. The incidence rate of liver cancer among Hmong in California is nearly six times higher than that

of non-Hispanic Whites, and because hepatitis B screening is low among the Hmong they also experience the lowest rate of survival from liver cancer than any other Asian ethnic group (Chen et al., 2013). Hmong women have been shown to have received screening for breast and cervical cancer at unacceptably low rates, which may lead to late-stage cancer diagnosis (Fang, Lee, Stewart, Ly, & Chen, 2010; Kagawa-Singer, Tanjasiri, Valdez, Yu, & Foo, 2009; Tanjasiri et al., 2001; Yang, Mills, & Dodge, 2006). In addition, cervical cancer incidence for Hmong women is 4.2 times higher than that of non-Hispanic White women (Yang, Mills, & Dodge, 2004). The lack of cancer screening among Hmong women has been attributed to cultural and traditional health beliefs (Baisch, Vang, & Peterman, 2008; Her & Culhane-Pera, 2004; Parker & Kiatoukaysy, 1999). For example, Hmong culture is patrilineal and patriarchal; traditionally, medical decisions are made by the male head of household (Cha, 2003). Thus Hmong women may not have the autonomy to make their own cancer screening decisions. Further, the Hmong's beliefs in the spiritual etiology of cancer and their fatalistic attitudes toward cancer have been identified as potential barriers to cancer screening (Baisch et al., 2008; Lee & Vang, 2010; Parker & Kiatoukaysy, 1999). To better understand the influence on cancer screening behavior among Hmong women, we conducted the Hmong Breast and Cervical Cancer Project with Hmong women and men in Oregon and examined the social, cultural, and health care system factors that may influence breast and cervical cancer screening for Hmong women.

Lessons Learned

Working with the Hmong community presented unique research opportunities and challenges. This article shares lessons learned during the process of planning and conducting this research study. We draw information from research team discussions, insights from our Hmong research team members, input from the Community Advisory Committee, and project documents. We describe the challenges that we experienced carrying out this research project, and the lessons we learned from our experiences organized around topics and themes. These lessons have the potential to provide guidance to researchers on methodological and practical issues related to conducting research with this population and possibly similar populations.

The Hmong Breast and Cervical Cancer Project

We conducted key informant interviews, followed by in-depth interviews with Hmong community members in Oregon. The academic research team included two investigators, one of whom was Hmong and a member of Oregon's Hmong community. Research team members also included bilingual and bicultural Hmong interviewers. These individuals were recruited from the community, trained by the investigators in project-specific procedures, and assisted with recruitment and data collection for the in-depth interviews. The primary geographic focus of the study was the Portland metropolitan area where most Hmong in the state reside and, secondarily, Marion County (Salem, OR) where a smaller number live. Seventeen key informant interviews were conducted with Hmong community members and leaders between July and August 2009. Data from the key informant interviews informed the development of the interview guides to be used in subsequent in-depth interviews with community members. Between December 2009 and May 2010, 84 in-depth interviews were

conducted with Hmong women and men aged 18 years or older living in Oregon. The interviews took place in the participant's home or office, a community center, a library, or a Hmong church. The interviews were conducted in English, Hmong, or both, depending on the preference of the participant and were audio recorded. We then conducted content analysis of the transcripts using NVivo 8 (QSR International, Cambridge, MA). Details of our methods are described elsewhere (Kue, Zukoski, Keon, & Thorburn, 2014; Thorburn, Keon, & Kue, 2013; Thorburn, Kue, Keon, & Lo, 2012; Thorburn, Kue, Keon, & Zukoski, 2013). The study was approved by the Oregon State University Institutional Review Board.

Cultural Insider as Investigator

Importantly, one of the study's investigators was a bilingual, bicultural Hmong woman. Throughout most of the project, she was a doctoral student and worked closely with the Principal Investigator, who was her mentor. She played a critical role in building and maintaining support for the project. She had served on the board of a local Hmong community-based organization and had well-established relationships with community leaders and organizations. Before the project, she had worked and volunteered with various programs directed at improving the health of the Asian and Pacific Islander communities in the Portland metropolitan area. She helped to develop partnerships with local Hmong community members and gain the support of community leaders during the early phases of project development. She introduced other members of the research team to community leaders and facilitated the development of those relationships. She participated in all phases of the project, serving as a critical link between the research team and the Hmong community. She shared with the research team her knowledge of diverse topics in the local Hmong community, such as Hmong beliefs about health and illness, cultural norms regarding gender roles, literacy and language issues, the role of clan leaders, and local community leaders and organizations. As project coordinator, she managed field work, supervised interviewers, led and participated in recruitment activities, and conducted some of the key informant and in-depth interviews. She also participated in data analysis and took a lead role in manuscript preparation.

Challenges—Because the co-investigator is Hmong and from the community, some participants may have expected her to understand what they were discussing (e.g., the cultural nuances) and, therefore, may not have elaborated on their responses. The co-investigator had to be consciously aware of her own knowledge of the Hmong culture and try to illicit detailed responses from participants so that non-Hmong research team members would have an understanding of the content. This challenge was not specific to the role of a co-investigator; rather, it pertained to the unique position of being a bicultural (e.g., interviewer and community member) researcher. Each of the bilingual, bicultural Hmong research team members were trained to prompt participants to elaborate on any responses that could be unclear. Additionally, some community members treated the co-investigator as a confidant, rather than someone who was more objectively interviewing them. Participants openly shared other health concerns or information unrelated to the study. For example, one participant, a Hmong shaman, wanted the co-investigator to take some of his medicinal herbs to have it tested for its effectiveness in treating hepatitis B. Other participants talked

about health conditions or illnesses that ailed them. These types of responses were shared with the co-investigator, perhaps because of her more authoritative role as a co-investigator.

Lessons learned—Having an investigator who was a member of the community was vital to the project. Her knowledge of Hmong culture and the local Hmong community was critical to the conception of the research idea and development of research questions and culturally appropriate materials and methods. She also helped to select a Hmong post-baccalaureate as a research assistant (funded through a supplemental grant). There are few Hmong investigators conducting public health research. It was important for both her and her mentor to engage other Hmong in conducting this community-based research with the Hmong, as well as develop her (the co-investigator's) own skills and experiences to become a leading researcher in this field. Furthermore, she played an essential role in personally inviting key leaders of the Hmong community together and getting their support for the project, establishing the Community Advisory Committee, keeping committee members engaged and communicating with them throughout the project, and maintaining their support and involvement. She worked closely with and supervised the interviewers who were hired from the community and had no research experience; her ability to connect with the interviewers as a member of the community was critical to their training. Because the co-investigator had prior research experience, as well as knowledge of Hmong cultural norms, she could convey the research protocol to the interviewers by using culturally relevant examples such as when discussing recruitment strategies, issues of privacy and confidentiality, and interviewing techniques. For instance, she and the Hmong research assistant role played different scenarios during the interviewer training on how to handle issues related to privacy and confidentiality when faced with a family member or community leader who wanted to know if a particular person from the community was involved in the study. She was also able to help solve issues related to translation of words and phrases in the interview guide, as well as strategize where to recruit participants and how to handle unforeseen data collection issues (e.g., interview location, privacy). In addition, her participation in data analysis ensured that our interpretation of the data was grounded in an understanding of Hmong culture and the Hmong community in Oregon. Our project exemplifies the vital contributions, as detailed above, to be made by cultural insiders when involved as investigators or contributors to the development of research ideas, questions, and appropriate study designs.

Building Community Partnerships and Support

We took several steps to build relationships with community members and gain support for the project several years prior to securing funding for the study. First, the investigators spent time meeting and discussing the project with community leaders during project design and development. As suggested above, the investigator who was a member of the community introduced the Principal Investigator to key community leaders. She arranged for and led the meetings between the research team and community leaders. During those initial conversations and meetings, the community leaders provided invaluable input into and support for the development of the proposal and suggestions for the Community Advisory Committee. Community leaders provided letters of support for multiple grant submissions,

and they agreed to serve on the Community Advisory Committee and assist with recruitment once the project was underway.

Second, once the study was funded, the research team formally established the project's Community Advisory Committee. We invited additional community members to join the committee. These individuals were identified by the Hmong investigator and the community leaders who had already agreed to serve on the committee as leaders in the community and/or community members who had experience and perspectives that would be beneficial to the project. In total, the committee consisted of six Hmong community leaders and three additional Hmong community members. The members had one or more of the following positions or roles: clan leaders, the director of a community-based center (described further below), managers at state health and human service agency or county health department, leaders of the two local Hmong community organizations, a church leader, one physician and one medical student, a shaman, and persons with strong interest in cancer. The members represented 5 of the 17 Hmong clans in Oregon.

Committee members helped to introduce the project to community members, and they gave their endorsement and support of the project when interacting with community members. Given the roles of clan and community leaders in Hmong culture, the support we received from the Community Advisory Committee ensured credibility for our study and greater acceptability by the Hmong community, consistent with the principles of community-based research (Minkler & Wallerstein, 2002). The committee also identified community assets and resources (e.g., strong family ties, social support) to consider in study design, provided input into the development of culturally appropriate recruitment and data collection procedures, participated in problem-solving (e.g., how to increase recruitment), and helped liaise with community organizations and members (e.g., to demonstrate their support for the project and thus garner the support of community members, to introduce team members as part of recruitment). They provided feedback on the initial study design and methods. Other examples of committee involvement include assisting with development of the list of clan names and with translations of recruitment materials (e.g., brochures and postcards). Committee members helped to interpret results and share results back to the community. In addition to discussions at the meetings, we asked individual members of the committee for advice throughout the project on topics ranging from hiring staff to translation of study materials to the appropriateness of female field staff interviewing male participants.

Third, we gained the support of a local community-based center, which was not only well-known and highly regarded by the Hmong community, but also served the Hmong through programming. The director of the organization, who is Hmong and a Hmong community leader, agreed to provide space from which we could coordinate and oversee recruitment and data collection, as well as build community trust and support for the project. In addition to being a convenient location for overseeing and coordinating field work, a physical presence at the Center contributed to the perceived legitimacy of the project within the local Hmong community. The Center also assisted with recruitment and promotion of the project (e.g., allowing us to post flyers about the project, providing space for conducting interviews) and hosted the Community Advisory Committee meetings and some research team meetings. The Center also hosted an open community meeting at which study findings were

disseminated. In essence, the Center served as an avenue for outreach and dissemination with community members.

Challenges—Challenges related to the Community Advisory Committee did not present significant barriers to the implementation or completion of the project. First, despite our flexibility with the timing of meetings, it was challenging to hold a meeting at which all committee members were present. In addition, some members of the committee (especially younger members and women) did not participate in discussions as actively as other members, perhaps due to the different roles committee members had in the community (e.g., clan leaders) and cultural norms around showing respect to elders and male leaders. Furthermore, the younger committee members (one physician and one medical student at the time of data collection) were fairly new to Oregon, and they may have contributed less to discussions because they were not as familiar with the local Hmong community as the other longstanding community members.

Lessons learned—Building community partnerships early in the project development phase strengthened our grant application, ensured that we had community support before the project's initiation, and made the transition from grant application to project implementation go smoothly. Having physical space in a conveniently located community-based organization increased awareness of the project, made recruitment and data collection easier, and facilitated community members' participation in the advisory committee. The committee provided input to help ensure that the project was culturally sensitive and appropriate. Their involvement in the project was fundamental to the project's success. For this study, we wanted to include younger members of the community so that we could have diverse opinions. In addition, including the younger individuals on the Community Advisory Committee was important because both had medical backgrounds (one doctor and one medical student), which we felt could be helpful in terms of medical terminology. Also, as a doctor, the one advisory committee member had a position of status that could be beneficial. It is important to note, however, that having advisory board members who are well connected to the community is key to successful community participation. Community involvement and relationship-building are critical for building trust and are basic principles of community-based research. Researchers can alleviate barriers to recruitment and ensure greater community involvement by developing relationships with key community partners and engaging them early in the research process.

Hiring and Training Bilingual and Bicultural Staff

In addition to having a Hmong investigator on the research team, the field staff consisted of bilingual and bicultural members of the Hmong community. We applied for and received an administrative supplement through the National Institutes of Health's program for research supplements to promote diversity in health-related research. The diversity supplement allowed us to hire another Hmong research team member as a research assistant. According to 2000 Census data, less than one one-hundredth of a percent of Hmong women obtain a PhD (Niedzwiecki & Duong, 2004). The person we hired was post-baccalaureate and interested in gaining experience in public health research. In addition to participating in

career development activities, she provided general research assistance and participated in recruitment, data collection, data management and analysis, and manuscript preparation.

Additionally, we hired and trained bilingual, bicultural staff to assist with recruitment and to conduct interviews. We sought and hired one female interviewer and one male interviewer, so that the interviewers and participants could be matched according to gender (as data collection progressed, the male interviewer left the project; subsequently men were interviewed by female members of the research team). These additional staff had no prior research experience, but had characteristics and/or skills that were important for the positions; for example, they were respected members of the community, had strong community ties, their age (i.e., late 40s) was culturally appropriate for interviewing older and younger participants, and they were highly fluent in Hmong.

To prepare field staff for recruitment and data collection activities, we conducted a two-day training, which covered topics such as recruitment and data collection materials and procedures, data management, the informed consent process, and how to deal with issues of confidentiality in a small community. This initial training was followed by ongoing training and monitoring (e.g., weekly meetings between co-investigator and field staff to go over procedures and the interview guide). All four Hmong research team members, including the co-investigator, conducted recruitment and interviews.

Challenges—We advertised for interviewer positions via word-of-mouth and local Hmong organization e-mail listservs. These efforts yielded a very small pool of candidates for interviewer positions, and none of the candidates had research experience. As noted, the Hmong are a kinship-based culture, which posed another challenge in that Hmong project staff may have been immediate or extended family members to potential and actual participants. This relationship may have affected staff's comfort interviewing some potential participants, as well as some participants' comfort with being interviewed by staff, both positively and negatively. The Hmong community in Oregon is small, and the chances of knowing one another are fairly high. This situation may either deter individuals from participating in the study because of disclosure of personal information or they may be more willing to participate and feel comfortable being interviewed by another Hmong person. Furthermore, training, ongoing training, and monitoring field staff was very labor- and time-intensive. Because interviewers did not have research experience, they required additional time to feel comfortable with the recruitment and data collection process and to know the procedures. We continuously trained interviewers about the purpose of research protocols, following IRB-approved protocol to protect participants, monitoring data collection, and consistently keeping track of records. Another challenge was that the Hmong's written language was developed in the 1950s by missionaries, and many Hmong do not read and/or write their own language. For instance, the Hmong investigator on the research team spoke Hmong, but did not read or write Hmong.

Lessons learned—Although we expected training to be a major task, we still underestimated the amount of time needed to review and monitor procedures with field staff. Researchers should plan for and dedicate substantial amounts of time for recruiting, hiring, and training staff, especially if individuals do not have experience with research. The co-

investigator met with interviewers individually on a weekly basis at the beginning of the study to review the protocol, practice the interview guide, and do some role playing. As interviewers became more familiar with the process, the training decreased. Also, we recommend that researchers consider issues of language and literacy early; many Hmong speak Hmong but cannot read and/or write Hmong. These issues may impact the desired qualifications for and abilities of field staff, which may have implications for other aspects of the project (e.g., data collection).

Using Culturally Appropriate Materials and Methods

Despite low Hmong literacy levels, we included Hmong text in recruitment materials (brochure, postcard) to demonstrate to the community our desire to be culturally appropriate and sensitive. We also used colors and symbols that are important and reflective of Hmong culture in the recruitment materials; specifically, we had a graphic designer create a project logo in pink and yellow that included an elephant's footprint and cucumber seeds, which are designs that are commonly used in Hmong *paj ntaub* (flower cloth) and are symbolic of things in nature to the Hmong. More specifically, the symbols could easily be recognized as something relating to the Hmong community if seen on recruitment materials in a store, restaurant, church, or community center where the Hmong frequent. We wanted these images to attract interest from Hmong individuals. Based on our understanding of Hmong literacy, we chose not to provide a written translation of the interview guide in Hmong; rather, for participants who preferred to be interviewed in Hmong, the bilingual interviewers translated the questions as they conducted the interviews. Interviewers went through rigorous training on how to ask questions in Hmong so that the meaning of those questions would be retained.

As noted above, we conducted key informant interviews with members of the Community Advisory Committee and other community members. One purpose of these interviews was to obtain input on procedures for in-depth interviews. To gain the trust of potential participants, Community Advisory Committee members provided field staff with introductions to clan leaders and other community members. In addition, we conducted data collection in locations that were familiar and comfortable for members of the Hmong community. We also conducted recruitment and data collection activities in English, Hmong, and a combination of the two.

Challenges—The greatest challenges associated with developing culturally appropriate recruitment materials (e.g., postcard and brochure) involved translation. Project staff and Community Advisory Committee members did not always agree on the correct and/or preferred translation of some Hmong words and phrases. For some text, deciding on the Hmong translation required extensive discussion, and in some instances the final decision did not meet everyone's preferences. In addition, some specific words or concepts do not have Hmong equivalents (e.g., the words “cancer” and “cervix”). Thus, translation was a group process, and in a few instances ended in compromise rather than consensus.

Lessons learned—Researchers should expect the translation process to be time-intensive and require the involvement of multiple people. Standard procedures for translating text may

not be desirable due to differences in opinion about correct and/or preferred terms. However, by taking a community committee approach to translating, researchers can ensure that study materials are translated correctly and are culturally sensitive to variances in language (Harkness & Mohler, 2002). Researchers should also consider whether investing resources in translating the data collection instrument is worthwhile, as the cost for translation can be expensive and some Hmong staff may be unable to read documents in Hmong. Based on our experience, we recommend using rigorous training on how to ask questions or say certain words in Hmong so that meaning is retained when conducting research in cultures that are predominately oral versus written. For example, there is not a Hmong equivalent for the word 'cervix'. The Community Advisory Board and research team discussed and came to a consensus on how to describe the cervix so that it was not only appropriate, but also accurate. Interviewers were trained and subsequently trained on the explanation of the word cervix. The initial and ongoing input from Hmong team members and Community Advisory Committee members was essential for identifying culturally appropriate methods and procedures.

Conclusion

We highlighted four key areas of the research process that contributed to the success of our study with a community that has little experience with research: engaging cultural insiders as investigators, building community partnerships and support; including members of the community on the research team; and developing culturally appropriate and sensitive methods and materials. These are important factors to consider when conducting research or implementing interventions with a small, kinship-based community. Major challenges involved time-intensive training and supervision of field staff and difficult translation of research materials. The challenges we experienced were not difficult to overcome, but underscore the need to be sensitive and flexible in conducting community-based research with the Hmong. We hope that the lessons learned from our study with the Hmong will provide guidance for doing future research with this underserved population or other similar populations.

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